Modifications of the Home Environment and Routines in Families of Children Diagnosed with an Autism Spectrum Disorder

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Abstract

The purpose of this study was to identify caregiver-implemented modifications of routines and home environments in families of children with an autism spectrum disorder throughout the U.S. that are believed to facilitate the child's enhanced participation in daily life. A survey was completed by 50 primary caregivers of children with an autism spectrum disorder in the western, northeastern, and southern regions of the U.S addressing the type and frequency of modifications. Routines for dressing (42%), bathing/grooming (52%), and sleep-related activities (86%) were the most commonly reported modifications used sometimes to always within each area of occupation. Other frequently used modifications included (1) using elastic to avoid buttons and zippers (38%), (2) using a particular toothpaste (44%), (3) allowing the child to use a preferred bathroom (26%), (4) allowing the child to eat with hands or preferred utensils (50%), (5) serving only the child's preferred food (46%), and (6) providing the child with a favorite object during sleep-related activities (59%). Across all examined areas of occupation, sleep-related activities were the most commonly modified sometimes to always (48%). A history of receiving in-home therapy services, including occupational therapy, was associated with a higher frequency of implementing home modifications. In conclusion, the establishment of routines and implementation of environmental modifications may be so frequently used by caregivers because of their impact on the child's participation in daily activities.

Modifications of the Home Environment and Routines in Families of Children with an Autism Spectrum Disorder

Human beings are inherently adaptive creatures that possess the capacity to change markedly in response to their environment. A common, powerful, and globally experienced cause of adaptation is raising a child. Parents often modify their lifestyle and the household to accommodate their child and to provide a better quality of life for their family. Individuals enact such changes to varying degrees. Parents raising a child with a developmental disability, such as an autism spectrum disorder (ASD), often modify family routines and environments to a much greater extent (Bagby, Dickie, & Baranek, 2012). Due to the substantial impact of an ASD on the individual with the disability and on the entire family unit, therapeutic intervention and parent modifications are important for establishing, restoring, and maintaining family quality of life (Whitney, 2012).

Recent occupational therapy literature has identified that raising a child with an ASD is a dominant stressor in parental and familial relationships (Weiss & Lunsky, 2011). From the parents' perspective, the child requires constant attention, flexibility from the family unit, continuous financial resources, and modifications to family life (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Stressors that place additional demands on caregivers may contribute to parental depression, poor sibling adjustment, marital tension, and a diminished quality of life for the entire family (Luthman, 2010; Schaaf et al., 2011). Through occupational therapy, these stressors may be indirectly alleviated by increasing function and participation in valued family activities.

Occupational therapy (OT) focuses treatment within the context of the individual's natural environment. A child's primary environment for development is the home. Areas of

occupational performance that occur within the household include activities of daily living (ADL), such as dressing, grooming, feeding, bathing, and toileting, as well as play, social interaction with family, and establishment of habits and routines (American Occupational Therapy Association [AOTA], 2008). Occupational therapists working with children who have an ASD possess the skills to empower families by providing strategies, routines, and the designs for environmental modifications in the home. Caregiver implemented accommodations are known to increase participation in family occupations and establish a healthy functioning family unit (Luthman, 2010; Werner DeGrace, 2004). Parental modifications of the home environment and of routines may help decrease the common stressors associated with raising a child with autism (Kashinath, Woods, & Goldstein, 2006; Pengelly, Rogers, & Evans, 2009).

Occupational therapists have the potential to impact the family unit through delivery of home interventions; however, there is limited research on the specific areas of occupation families identify as most in need of intervention. Primary caregivers of children with an ASD are an underutilized resource who can provide rich knowledge about successful implementation of home accommodations. This population has the potential to help occupational therapists gain an enhanced understanding of modifications that support the child and create a healthier family environment.

Background

The most recent data from the Centers for Disease Control and Prevention (CDC) estimated that 1 in 88 children in the U.S. have been diagnosed with an ASD (2012). There has been a steady rise in the prevalence of ASD over the past decade as evidenced by the growth from the year 2000 when 1 in 150 children were estimated to have the condition (CDC, 2012). Autism spectrum disorders include autistic disorder, pervasive developmental disorder – not

otherwise specified (PDD - NOS), Asperger syndrome, Rett's syndrome, and childhood disintegrative disorder (American Psychiatric Association [APA], 2000). Although there is variability in the severity of the disorder for each child, there are distinguishing characteristics representative of ASDs.

An ASD is typically diagnosed before the age of three. Symptoms can persist throughout the lifetime. Clinically referred to as associated features, common characteristics of individuals with an ASD that effect daily performance include: sensory processing impairments, communication and language delays, social challenges, ritualistic behaviors, perseveration of thoughts, inattention, impulsivity, and disregard for safety (APA, 2000). As a result, participation in daily occupations, such as dressing, eating, and toileting, can be significantly impacted (Rodger & Umaibalan, 2011; Werner DeGrace, 2004). A study by Turner-Brown, Lam, Holtzclaw, Dichter and Bodfish (2011) compared the restricted and repetitive behaviors of children with an ASD to those of children without a diagnosis. They found that while there was no difference in the intensity of interest in objects, there were significant differences in frequency of play, caregiver accommodations, and lack of inclusion with others, leading to parent-reported challenges that indicated increased levels of dysfunction.

Participation in the home environment is a primary area of occupation impacted by the functional challenges of a child diagnosed with an ASD, affecting the health of the family unit (Schaaf et al., 2011). One agreed upon measure of a healthy family is the ability to meet daily challenges successfully (Rodger & Umaibalan, 2011). Parents have identified unique daily challenges raising children with autism, such as poor routine development and unpredictable behavior, which make it difficult to meet the demands of daily life (Case-Smith, 2004; Marquenie, Rodger, Mangohig, & Cronin, 2010). Werner DeGrace (2004) identified common

themes related to the impact of raising a child with an ASD, including the perceptions of the family unit revolving around the diagnosis, being deprived as a family, and fleeting moments of feeling like a family. Bilgin and Kucuk (2010) found financial problems, feelings of physical or mental exhaustion, and feeling alone were related to increased stress and feelings of helplessness among Turkish mothers of children with an ASD. Due to varying cultural roles, the identified stressors from the study may be less generalizable to families in the U.S.

In an attempt to establish or restore participation in family occupations, caregivers provide environmental and routine accommodations for their child. According to Segal (1999) family occupations are defined as "culturally meaningful chunks of activities [occurring] when the whole family is engaged in an occupation together" (p. 1). Bagby et al. (2012) discussed mealtime, bedtime, and bath time as parent-identified meaningful occupations because they allow for conversation among family members and engagement in meaningful family activities. The study compared responses of families with typically developing children and families of a child with an ASD. It reported meaningful family occupations required increased preparation and planning for those families of a child with autism. Family preparation included: modulating sensory experiences such as providing a child with ear plugs before using a food processor, wetting a paper towel at breakfast to avoid the sticky feeling of syrup on the child's hands, and pre-planning exit strategies if the family was going to an event with high sensory stimuli (Bagby et al., 2012).

For the purpose of the current study, routine is defined as "patterns of behavior that are observable, regular, repetitive, and that provide a structure for daily life" (AOTA, 2008, p. 643). Routines are established to provide a structured sequence of steps that ensure consistency and predictability. Environment is defined as "the external physical and social [contexts] that

surround the client and in which the client's daily life occupations occur" (AOTA, 2008, p. 642). Examples of routines include school preparation, mealtime, bath time, bedtime, and transitions between activities. When referring to the home environment, all areas of the home where occupations take place are included, specifically, the living room, play areas, including outdoors, bedrooms, kitchen, dining rooms, and bathroom. A common morning routine for school preparation may include waking up the child, using the bathroom, dressing appropriately for the weather, brushing teeth and hair, sitting at the table to eat breakfast, placing necessary school supplies in backpack, and waiting at the bus stop until the bus arrives. A family with a child diagnosed with an ASD may modify this routine and many others in order to accommodate the associated features of the child's diagnosis such as possible sensory challenges, language delays, and distractibility (Spitzer, 2010).

Due to individual challenges, interventions and adaptations need to be specific to the child's needs. Pengelly et al. (2009) found some families of children with an ASD benefitted from a room adapted into a personal, emotional, and occupational space specifically for the child. Although only three families participated in the study, these results support the importance of a modified home environment. Meszaros (2008) surveyed families of children with autism who reported that environmental modifications, such as removing clothing tags and allowing a child to eat with their hands, were more frequently implemented than structural modifications, such as alarm systems or additional locks. Additionally, individual adjustments of the caregiver and consistency in routines allowed the child to successfully complete activities, including dressing and play, inside and outside the home (Kashinath et al., 2006).

Occupational therapy was founded on a client-centered philosophy, viewing the individual through a holistic lens, assessing not only client factors interfering or promoting

function, but also considering the individual's environment and occupational performance. Occupational therapists aim to improve health by establishing, maintaining or restoring an individual's sense of identity through participation in valued and essential daily activities. They promote functioning in natural environments. Self-care, play, and social skills are a few areas of development fostered in the naturalistic setting of the home (Luthman, 2010). The individual needs of children are identified and addressed in collaboration with the client and caregivers, in order to promote healthy family functioning.

Occupational therapists are experts in partnering with caregivers to discuss ideas for intervention and modification to increase their child's participation in family occupations. In addition, therapists provide caregiver education through training, observation and feedback, in hopes of facilitating generalization of the child's skills in daily activities. Education and collaboration promote caregiver confidence and encourage active participation in the child's therapy, ultimately leading to better therapeutic outcomes in the home.

Caregiver implemented home interventions have been found to be successful (Bendixen et al., 2011; Schertz & Odem, 2007). In Bendixen et al. (2011) perceived parental stress of 19 families of a child with an ASD was measured before and after a "father-based intervention." Fathers were trained by occupational therapists in techniques, such as following the child's play and imitating movements, to use with their child to promote social interaction and increase parent-child reciprocity. Fathers then taught techniques to the mothers who further incorporated them into the home environment. At the end of a 12-week intervention, perceived stress scores, as measured by the Perceived Stress Inventory (PSI), had significantly decreased among mothers and fathers. Due to decreased stress, families were better able to engage in meaningful home occupations.

Supporting the previous study, Schertz and Odem (2007) conducted "parent-mediated intervention" with three mother-toddler dyads. Mothers were taught strategies to increase joint attention while playing with their child with autism. Joint attention was operationally defined as "visually coordinating attention with a partner to an external focus showing social engagement and an awareness of the partner's mutual interest…" (p. 1562). In a multiple baseline design, pre- and post-test variables of turn taking, focusing on faces, and initiating and responding to joint attention were measured using the Joint Attention Mediated Learning (JAML) protocol, developed by Schertz. All three children surpassed baseline performance levels on the four outcome variables previously outlined. Despite the small sample size, it is reasonable to attribute the achievements of children's outcomes to the family-centered intervention approach within the home and the naturalistic context of the parent-child relationship for social-communicative learning.

Additionally, Kashinath et al. (2006) examined the effect of parent-implemented interventions embedded in two daily routines on children who had autism. Parents were provided with two of three teaching strategies – contingent imitation, time delay, and environmental arrangement – aimed at improving the child's communication skills through vocalization within all daily routines. Analyses of videotaped observations were used to determine findings. Significant improvements were seen in the children regarding communication. In addition, parents were able to generalize the use of the above strategies. Although the researchers chose to target routines most likely to improve from an intervention, these findings support the effectiveness of a variety of caregiver-implemented interventions.

Many of the studies previously mentioned focused on child communication and caregiver roles needed for their child to be engaged in social participation, play, and education.

Occupational therapists recognize the essential need to maintain a wide range of interventions for families of children with an ASD. Each family presents specific challenges and it is the role of the occupational therapist to provide strategies that support the child's occupational performance and ultimately restore or establish better family health. Collaboration between the caregiver and occupational therapist is valuable in identifying areas of occupation that need to be addressed during treatment and generalized to the home; however, there is a void in the research regarding environmental modifications and routines implemented for ADL and instrumental activities of daily living (IADL) in the homes of children with an ASD.

A primary need for current research is to identify challenging areas of occupation where improvement would be most important for families, specifically ADL dressing, bathing and grooming, toileting, and eating/mealtime, sleep-related activities, and IADL meal preparation and household chores. Activities of daily living have been highlighted clinically as an area of challenge for children with an ASD (Spitzer, 2010); however, there is little empirical data to support this claim. Meszaros (2008) found that families of children, ages 3 to 17 years old, with a diagnosis of autism in Tacoma, Washington, identified ADL as the most important area of occupation where modifications were needed. Dressing, bathing and grooming, and eating were identified as the most common areas in which parents reported implementing environmental modifications. Furthermore, allowing the child to wear only preferred clothing, allowing the use of the child's preferred toothpaste, and serving only the child's preferred foods were the most reported modifications used in the specified ADL, respectively (Meszaros, 2008). The researchers believed that by targeting these needs occupational therapists could support the child's functional performance and help improve the overall health of the family unit.

Currently there is limited research addressing modifications to ADL and IADL

performance in the home of children with an ASD. To extend this pilot project, the current study sought to geographically broaden the perspective by including participants from a national sample of families in three regions of the U.S. The purpose of this study was to identify caregiver-implemented modifications of routines and home environments in families of children with an ASD that are believed to facilitate the child's enhanced participation in daily life.

Method

Research Design

The present descriptive study aimed to identify caregiver-implemented modifications in the home of families seeking to accommodate children with an ASD. A survey was used to collect data on specific modifications to routines and the home environment that facilitated the child's participation in life. A survey design was chosen by the researchers as the ideal methodology to reach a national sample and to maintain consistency with the pilot study conducted by Meszaros (2008); however, her survey distribution was in-person at support groups for families of children with autism in the Tacoma area. The present study collected data from private clinics. Potential limitations to this design were leading or unclear questions and questions that do not elicit answers addressing the study's purpose, thus weakening content and construct validity. An inherent limitation to survey design is a possible response bias from the survey recipients.

Participants

The population of interest was primary caregivers in the home of children with an ASD throughout the U.S. In an effort to maintain focus on the population of interest only families with children who had a primary diagnosis of an ASD were included in the study. If the child had a primary diagnosis of an ASD and a secondary diagnosis other than an ASD, the participant met

the inclusion criteria. A sample of convenience was acquired using the research chair's connections with occupational therapists working in private clinics throughout the nation. The chair worked as a clinical assistant professor at the university. She is the research and education liaison for the AOTA Sensory Integration Special Interest Section (SISIS) and teaches a Comprehensive Course in Sensory Integration for USC/WCS in Los Angeles, California. The research chair contacted 23 private clinics throughout the four geographic regions and 12 agreed to participate in the study. The remaining 11 private clinics did not participate due to discrepancies with IRB approval, limited number of clients meeting the inclusion criteria, or non-response. Agreement to participate in the study was confirmed through email or telephone contact.

Primary caregivers meeting the inclusion criteria were asked by the administrative assistant or occupational therapist at the private clinic where the child received services if they wanted to participate in the current survey. A flyer was provided for each clinic to generate interest of potential participants. Those who agreed to participate were given a packet containing materials needed to complete and return the survey to the researchers. The packet contained a cover letter explaining the purpose and participant consent, the survey, and a postage-paid return envelope. Surveys were sent to three geographic regions throughout the U.S. No states in the midwest were included in the survey due to discrepancies with the IRB and no return contact from occupational therapy private clinics in the region. Based on an estimated sample size of 240 surveys, approximately 100 surveys were sought in order to be able to report findings with 95% confidence, assuming the population is relatively varied. The return of a completed survey was considered consent by the participant to use the collected information in the results of the study, as explained to participants in the cover letter.

Instrumentation

The present study used a modified version of the Meszaros (2008) survey examining environmental modifications made in the homes of children with autism. Changes to the survey were supported by current research, including Meszaros' (2008) results, which indicated that ADL was the most commonly modified area of occupation. The current survey removed sitting and attending to a task, play, keeping the child calm, safety, and equipment changes in the home, and added an IADL section. Adaptations were made to decrease the length and to narrow the focus of the survey, highlighting home modifications made regarding ADL, sleep, and IADL. The survey investigated areas of occupation addressed in the Occupational Therapy Practice Framework (OTPF) including ADL for dressing, bathing/showering, toileting, eating/feeding, IADL of communication and helping in the home (i.e., folding clothes, setting the table), activity transitions, and sleep-related activities (AOTA, 2008). The survey used closed-ended, "yes" or "no" questions supplemented by a four option Likert scale items to elicit more detailed responses. Demographic questions and an opportunity for comments or clarification were included in the survey.

Procedures

After review and approval from the university Institutional Review Board (IRB), the modified survey was piloted on four primary caregivers of a child with an ASD. Feedback was used to make slight formatting adjustments. Contact information for participating private clinics was gathered by researchers and telephone or email contact was made to request their assistance with the study and inquire about clinic procedures or institutional protocol. Upon agreement, private clinics were sent a package containing a list of package contents and directions, a script for distribution, a flyer, a copy of the study's purpose, procedures, and IRB approval, and the 20

survey packets (refer to Appendices A & B for sample survey and package contents). Packages were sent to two private clinics in the northeast region, six to the south region, and four to the west region. Caregivers who met the inclusion criteria were asked by the administrative assistant or occupational therapist if they wanted to participate in the current survey. Those who agreed to participate were given a packet. A follow-up phone call or email was made to the facility four weeks after the survey packages were mailed. Researchers inquired about distribution of the surveys and addressed any questions or concerns.

Data Analysis

The Statistical Package for the Social Sciences (SPSS) Version 19 was used for data input and analysis. Frequency distributions were used to report types of modifications and the regularity with which they were reported. Demographic and geographic data were portrayed through frequency distributions. All ADL, IADL, and sleep-related activity subsection questions were scored from 1 to 5 depending on reported frequency of modification implementation in the home (Never = 1; Rarely = 2, Sometimes = 3, Often = 4, Always = 5). A mean score for each respondent was derived by adding the reported frequency scores for each subsection question and dividing by the number of subsection questions answered. To find the mean score for the frequency of modifications made to each ADL, IADL, and sleep-related activity, all respondent subsection means were added together and divided by the total number of respondents (N = 50). Chi-square cross-tabulations were calculated between demographic and ADL and sleep-related activity modification variables. If an ADL or sleep-related activity subsection question was not answered, it was left blank. If a score was left blank, the total score was not calculated and therefore not included in the chi-square analysis.

Results

Respondent Demographics

Of the 240 sent surveys, 201 surveys were distributed, and 50 were completed and returned, for a response rate of 24.9%. Three of the twelve private clinics did not report the number of surveys distributed; therefore, it was assumed all 20 surveys were given to caregivers. Twenty-four (48%) of the respondents reported living in the south, 15 (30%) were from the west, and 11 (22%) were from the northeast. No returned surveys were excluded from the study. Partial data from two surveys were not recorded due to incomplete responses; for example, both respondents answered, "Yes" for the ADL and sleep subsections, but did not indicate frequency of use.

Of 50 children, 40 (80%) were boys. The children's ages ranged from 1 year to 17 years, with the plurality of children in the 4 and 6 years old category (18%). Twenty (40%) of the respondents reported having one other child and 11 (22%) reported having two additional children. The duration of time in which children have been receiving occupational therapy services ranged from 3 months to 12 years, with a plurality receiving 2 to 3 years of services (34%). Thirty-one respondents (62%) reported not receiving in-home therapy services from an occupational therapist or other medical professional. Of the 19 respondents who received in-home therapy services, 13 (68%) reported using suggested the caregiver-implemented modifications often.

Modifications of ADL Environments and Routines

Dressing. Twenty-six percent of the respondents reported using environmental modifications during dressing tasks sometimes to always. The most frequently used modification reported for dressing was following a specific routine. Twenty-one respondents (42%) used it

sometimes to always. The second most commonly implemented modification was using only elastic to avoid buttons or zippers. Nineteen respondents (38%) reported using this modification sometimes to always. Refer to Table 1 for the frequency of environmental modifications use in all dressing subsections.

Bathing and grooming. Thirty-one percent of the respondents reported using environmental modifications during bathing and grooming tasks sometimes to always. The most frequently used modification reported for bathing and grooming, as with dressing, was following a specific routine. Twenty-six respondents (52%) used it sometimes to always. The second most commonly implemented modification was using particular toothpaste that the child tolerates. Twenty-two respondents (44%) reported using this modification sometimes to always. Refer to Table 2 for the frequency of environmental modifications use in all bathing and grooming subsections.

Toileting and bathroom use. Fifteen percent of the respondents reported using environmental modifications during toileting and bathroom activities sometimes to always. Overall, modifications during toileting and bathroom use were the least used among all studied ADL areas. The most frequently used modification reported for toileting and bathroom use was allowing the child to use a preferred bathroom. Thirteen respondents (26%) used it sometimes to always. The second most commonly implemented modification was following a specific routine. Eleven respondents (23%) reported using this modification sometimes to always. Refer to Table 3 for the frequency of environmental modifications use in all toileting and bathroom use subsections.

Eating, mealtime, and snacktime. Thirty percent of the respondents reported using environmental modifications during eating, mealtime, and snacktime sometimes to always. The

most frequently used modification reported during eating and mealtime was allowing the child to eat with their hands or use preferred utensils. Twenty-five respondents (50%) used it sometimes to always. The second most commonly implemented modification was serving only what the child will eat (i.e., no new foods). Twenty-three respondents (46%) reported using this modification sometimes to always. Refer to Table 4 for frequency of environmental modifications use in all eating, mealtime, and snacktime subsections.

Sleeping. Forty-eight percent of the respondents reported using environmental modifications during sleeping and bedtime tasks sometimes to always. Overall, modifications during sleeping and bedtime tasks were the most used among all studied areas. The most frequently used modification reported for sleeping and bedtime was engaging in a routine or rituals when putting a child to bed. Forty-three respondents (86%) used it sometimes to always. The second and third most commonly implemented modifications were providing the child with a favorite object (i.e., stuffed animal) and adjusting lights to help with sleeping. Thirty-nine respondents (59%) and twenty-nine (53%) reported using these modifications sometimes to always, respectively. Refer to Table 5 for the frequency of environmental modifications use in all sleeping and bedtime subsections. Refer to Table 6 for a comparison of the percentage of use sometimes to always in all ADL and sleeping-related areas of occupation.

Chi-square cross-tabulations were calculated for ADL and sleep-related modification variables in relation to geographic region, child's age, number of siblings, and in-home therapy services. There was no significant difference in the reported use of modifications for geographic region, number of modifications for the child's age, and number of siblings. A significantly greater proportion of respondents who received in-home services, including occupational therapy, reported increased overall use of modifications compared to respondents who did not receive in-

home therapy services, $X^2(8, N = 41) = 23.07$, $p = 0.003$. A significantly greater number of respondents who also received in-home therapy services reported increased use of modifications for toileting compared with their counterparts, $X^2(8, N = 48) = 21.51$, $p = 0.006$.

IADL: Helping at Home

Twenty-nine percent of respondents reported that their child participated in IADL household tasks sometimes to always. Overall, the most frequently participated in IADL area were related to eating and mealtime (48%) and pet care (32%). Within each IADL area the most common tasks children were reported to engage in were mealtime cleanup and petting the animal sometimes to always (74% and 40%, respectively). Refer to Table 7 for the frequency of activities that support IADL performance in the home.

Means of Communication and Transition Methods

The primary means of communication for all identified ADL and sleep-related activities was verbal. The majority of the respondents did not report using one of the specified transition methods. Of the respondents who reported using a transition method, 48% reported using a timer and 43% reported using a schedule board. Transition methods were most frequently used with dressing activities (53%), where 23% reported using a timer and 15% using a schedule board. The second most frequently used area for transition methods was eating, mealtime, and snacktime (29%), where 9% used a schedule board. Refer to Table 8 for the frequency of communication and transition strategies.

Discussion

Respondent Demographics

The majority of the returned surveys were from the southern region of the U.S., which is most likely due to a majority of private clinics distributing the survey packets being located in

the south. Given the two-staged survey distribution process, the researchers consider the 24.9% response rate respectable.

Of the respondents who received in-home services, including occupational therapy, results suggest an increase in the frequency with which modifications were implemented compared to respondents who did not receive in-home services. Helping children develop skills in areas such as dressing and sleeping occur primarily in the home environment (Luthman, 2010). Occupational therapists have the knowledge and skills to work in the home with parents and children to provide specific modifications that fit the needs of individual families. Providing occupational therapy in the home may allow for specific modifications to be recommended with respect to the individual family needs, and therefore may be more frequently implemented.

Modifications of ADL Environments and Routines

Caregiver-implemented modifications to sleep-related activities were reported to occur most often (48%). Bathing and grooming (31%), and eating, mealtime, and snacktime (30%) were the second and third most commonly reported modified ADL. Meszaros (2008) also identified bathing and grooming, and eating as areas in which parents reported using many environmental modifications. Consistency between the Meszaros (2008) and current study highlight these areas as core concerns of caregivers raising a child with an ASD.

The most frequently reported modification used, secondary to following a routine, in each ADL and sleep-related activity was: 1) using only elastic to avoid buttons and zippers during dressing, 2) using a particular toothpaste during bathing and grooming, 3) allowing the child to use a preferred bathroom, 4) allowing the child to eat with hands or preferred utensils and serving only the child's preferred food during eating and mealtime, and 5) providing the child with a favorite object during sleep-related activities. Meszaros (2008) found similar

modifications used during bathing and grooming, toileting, and eating and mealtime activities, including using preferred toothpaste, using the child's preferred bathroom, and serving the child's preferred food. These specific modifications found across the two studies suggest their effectiveness for supporting the child's participation in ADL.

Routines during ADL and sleep-related activities were the most frequently used modification for 3 of the 5 examined areas, specifically dressing, bathing and grooming, and sleep-related activities. The current study found that 86% of respondents engaged in routines and rituals during bedtime. Meszaros (2008) found that 91.5% of the families engaged in routines or rituals when putting the child to bed. It is assumed that engaging in routines support the child's participation in ADL and sleep-related activities. A common strategy utilized by caregivers and occupational therapists to increase participation inside and outside the home is the implementation of routines during daily activities (Kashinath et al., 2006). Previous research has identified unpredictable behavior as a unique daily challenge for parents raising a child with autism (Case-Smith, 2004; Marquenie, et al., 2010); therefore, implementation of routines in the home may help accommodate for these unpredictable behaviors.

The current study found that environmental modifications were most frequently used for sleep-related activities. As outlined by the OTPF, rest and sleep includes engaging in rest, sleep, sleep preparation, and sleep participation activities that support healthy active engagement in other areas of occupation (AOTA, 2008). When compared to children without a diagnosed ASD, children with autism are at an increased risk for experiencing sleep-related difficulties (Schieve et al., 2011). Children with an ASD who experience these challenges display increased daytime symptomatic behaviors, such as affective problems, decreased attention, and higher reported levels on an anxiety/depressed scale (Malow et al., 2006). Previous research indicates that

sleeping has a significant effect on daytime activities; therefore, caregivers may have come to modify tasks related to sleep most frequently because of their powerful impact on a child's participation in daily activities.

IADL: Helping at Home

Participation in IADL related to eating and mealtime was the most commonly engaged in by children with an ASD (48%). Individual IADL-related tasks most frequently participated in were putting clothes away, cleaning up related to mealtime, and petting their animal. These opportunities for helping around the house increase the child's participation in the household and support establishment of roles in the family. All other cited research, including Meszaros (2008), did not address IADL participation, thus suggesting a current void in literature and need for future research.

Means of Communication and Transition Methods

Verbal communication was most frequently used in all areas of ADL and sleep-related activities, potentially due to ease of use across multiple environments and during a variety of activities. The use of verbal language does not require equipment, such as a picture exchange communication system (PECS) and augmentative communication devices, thus making it readily accessible to most caregivers. Although the present study found verbal as the most common method of communication, it is important to note that alternative means of communication have the potential to be highly effective for some children with an ASD (Mirenda, 2003).

In contrast to Meszaros (2008), the most frequently used transition method was found to be timers (48%), while Meszaros (2008) reported the use of charts/calendars of upcoming events to be the most common transition method (about 60%). A relative comparison of transition methods cannot be made due to the discrepancy between survey designs; however, this

information may be useful when establishing an ideal method for supporting a child through difficult transitions. Overall, transition methods were most commonly used for dressing activities. A potential explanation for this finding may be due to the inherent time constraints surrounding dressing. For example, if school begins at 8:45am, the child is expected to be dressed and prepared for school prior to that time; therefore, use of a transition method, such as a timer, may help improve time management and establishes expectations.

Implications for Occupational Therapy

Occupational therapists possess the skills and knowledge to work with clients and caregivers in their natural contexts. The current study suggests that in-home services, including occupational therapy, produce more regularly used environmental modifications; therefore, it is recommended that therapists with the opportunity for in-home visits should utilize this resource to provide modifications specific to the needs of their clients. No significant differences in frequency of modification use were found relative to the respondents' geographic region, age of child, and number of siblings; therefore, these variables may not need to be considered when suggesting modifications to a caregiver of a child with an ASD.

The use of routines has been highlighted in current and past studies as a frequently used caregiver-implemented modification in the home of children with an ASD in order to decrease common parental stressors related to raising a child with an ASD (Kashinath et al., 2006; Meszaros, 2008; Pengelly et al., 2009). In order to establish a routine that is specific to the child's needs, occupational therapists must collaborate with the caregiver to determine a routine that fits appropriately in the home and family context. Considering routines that support sleep and rest may be an essential area to address due to its impact on the child's performance in all daily activities. Occupational therapists should be proactive in discussing the child's sleep habits

with the caregiver, and if necessary suggest the use of a routine or other sleep-related modifications.

In order to support participation in the home, occupational therapists should suggest caregivers engage their child with an ASD in household activities, such as cleaning up after a meal and putting clothes away. These opportunities for helping around the house may establish the child's role in the family and increase interaction between family members to further strengthen familial relationships.

Limitations

A limitation of the present study was the two-tiered distribution process, which did not allow for the researchers to follow-up directly with caregivers receiving the surveys. Due to the research design, the data represents only a snapshot of modification use. This may not be representative of the population over time due to different caregiver modifications used to meet their child's evolving needs. Limitations may have resulted in an inaccurate representation of the national population. Although "optional" spaces for additional modifications for each ADL and sleep-related activity were provided in the survey, all possible modifications may not have been represented due to the difficulty of self-identifying modifications as they are intrinsically adapted into daily activities.

Future Research

Research in this area should attempt to access a sample that is more representative of the national population in order to provide accurate conclusions of caregiver-implemented modifications in the home. The sample should be sought from varying sources; for example, from private clinics and from support groups. An aim of future research should be to address the use of in-home modifications as related to perceived parental stress. A pre-test/post-test

methodology would allow for comparison of caregiver stress before and after implementation of the in-home environmental modifications. Additionally, a longitudinal study would provide insight into how caregivers change modifications over time as their child's needs evolve.

Conclusions

A survey was distributed to caregivers of children diagnosed with an ASD throughout the U.S. to determine common caregiver-implemented modifications of routines and home environments, as well as their frequency of use, that are believed to facilitate the child's participation in daily life. Results indicated that the use of a routine for ADL dressing, bathing and grooming, and sleep-related activities were the most frequently used environmental modification. Respondents who received in-home services, including occupational therapy, reported statistically significantly higher frequencies of modification use, thus suggesting effectiveness of in-home services. Occupational therapy should continue to collaborate with caregivers to provide in-home modifications for families of a child with an ASD to enhance the child's participation in daily life. A comprehensive list that may be valuable to occupational therapy practitioners of frequently used modifications determined in the current study are: 1) using only elastic to avoid buttons and zippers during dressing, 2) using a particular toothpaste during bathing and grooming, 3) allowing the child to use a preferred bathroom, 4) allowing the child to eat with hands or preferred utensils and serving only the child's preferred food during eating and mealtime, and 5) providing the child with a favorite object during sleep-related activities. In addition, sleep-related activities were the most commonly modified area of occupation addressed in the study. A possible cause is the impact of sleep on the child's participation in daily activities. Occupational therapists should consider beginning a dialogue with the caregiver regarding the child's sleep-related habits and modification use when necessary.

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Table 1

Frequency of Environmental Modifications Reportedly Used During Dressing Activities

	Frequency n (%)				
Environmental Modification	Never	Rarely	Sometimes	Often	Always
Remove tags of buy clothes without tags	26 (52)	6 (12)	9 (18)	2 (4)	7 (14)
Allow child to wear only his/her preferred clothes and/or brands	29 (58)	5 (10)	6 (12)	5 (10)	4 (8)
Buy seamless socks and/or other garments for child	43 (86)	2 (4)	0 (0)	3 (6)	2 (4)
Avoid clothing with elastic	45 (90)	2 (4)	0 (0)	1 (2)	2 (4)
Use only elastic to avoid buttons or zippers[b]	31 (62)	0 (0)	2 (4)	12 (24)	5 (10)
Lay out his/her clothing in a certain order	36 (72)	3 (6)	1 (2)	5 (10)	5 (10)
Follow specific routine to dress[a]	23 (47)	5 (10)	3 (6)	12 (24)	6 (12)

Note. In some subsections N < 50 due to incomplete responses.
[a]Most frequently reported modification used during dressing activities sometimes to always.
[b]Second most frequently reported modification used during dressing activities sometimes to always.

Table 2

Frequency of Environmental Modifications Reportedly Used During Bathing & Grooming Activities

	Frequency n (%)				
Environmental Modification	Never	Rarely	Sometimes	Often	Always
Avoid showers (use tub baths instead)	30 (60)	1 (2)	2 (4)	2 (4)	12 (24)
Minimize length of time/frequency of hair washing	32 (64)	1 (2)	2 (4)	7 (14)	8 (16)
Only use a certain type of comb or brush	40 (80)	2 (4)	2 (4)	3 (6)	2 (4)
Allow child to not brush hair	36 (72)	2 (4)	4 (8)	3 (6)	4 (8)
Use a special strategy for tooth brushing	37 (74)	1 (2)	2 (4)	0 (0)	10 (20)
Use a particular toothpaste which child tolerates[b]	26 (52)	1 (2)	2 (4)	7 (14)	13 (26)
Use special object (toy, earplugs, etc.)	37 (74)	2 (4)	2 (4)	4 (8)	4 (8)
Follows specific routine for bathing/grooming[a]	21 (42)	2 (4)	7 (14)	13 (26)	6 (12)

Note. In some subsections N < 50 due to incomplete responses.
[a]Most frequently reported modification used during bathing and grooming activities sometimes to always. [b]Second most frequently reported modification used during bathing and grooming activities sometimes to always.

Table 3

Frequency of Environmental Modifications Reportedly Used During Toileting & Bathroom Activities

	Frequency n (%)				
Environmental Modification	Never	Rarely	Sometimes	Often	Always
Use a schedule board with pictures/symbols to show bathroom times	43 (86)	3 (6)	2 (4)	1 (2)	1 (2)
Warn child before flushing toilet	38 (76)	3 (6)	4 (8)	2 (4)	3 (6)
Allow child to use only his/her preferred bathroom[a]	35 (70)	2 (4)	2 (4)	7 (14)	4 (8)
Use a special toilet seat for child	38 (76)	2 (4)	2 (4)	4 (8)	4 (8)
Use particular toilet paper or wipes, preferred by child	41 (82)	2 (4)	2 (4)	2 (4)	3 (6)
Allow child not to flush toilet, if frightened by it	40 (80)	5 (10)	1 (2)	2 (4)	2 (4)
Keep toilet paper out of child's reach	42 (84)	2 (4)	1 (2)	3 (6)	1 (2)
Use latch on toilet	47 (94)	2 (4)	0 (0)	0 (0)	1 (2)
Follows specific routine for toileting[b]	36 (72)	1 (2)	3 (6)	2 (4)	6 (12)

Note. In some subsections N < 50 due to incomplete responses.
[a]Most frequently reported modification used during toileting and bathroom activities sometimes to always. [b]Second most frequently reported modification used during toileting and bathroom activities sometimes to always.

Table 4

Frequency of Environmental Modifications Reportedly Used During Eating, Mealtime, & Snacktime

	Frequency n (%)				
Environmental Modification	Never	Rarely	Sometimes	Often	Always
Provide an alternative seating	35 (70)	2 (4)	5 (10)	2 (4)	3 (6)
Allow child to stand at table during meals	36 (72)	2 (4)	6 (12)	2 (4)	3 (6)
Serve food in preferred manner (i.e. not touching, one item per plate)	28 (56)	3 (6)	7 (14)	5 (10)	7 (14)
Allow child to eat with hands or use preferred utensils[a]	20 (40)	5 (10)	7 (14)	10 (20)	8 (16)
Serve only what your child will eat, no new foods[b]	23 (46)	4 (8)	8 (16)	10 (20)	5 (10)
Serve only a certain shape or color of food for your child	41 (82)	3 (6)	3 (6)	2 (4)	1 (2)
Serve only a certain texture of food for your child	36 (72)	2 (4)	5 (10)	3 (6)	4 (8)
Follows specific routine for eating	35 (70)	2 (4)	4 (8)	7 (14)	2 (4)

Note. In some subsections N < 50 due to incomplete responses.
[a]Most frequently reported modification used during eating, mealtime, and snacktime activities sometimes to always. [b]Second most frequently reported modification used during eating, mealtime, and snacktime activities sometimes to always.

Table 5

Frequency of Environmental Modifications Reportedly Used During Sleep-Related Activities

	Frequency n (%)				
Environmental Modification	Never	Rarely	Sometimes	Often	Always
Engage in routine or rituals when putting child to bed[a]	5 (10)	2 (4)	4 (8)	16 (32)	23 (46)
Provide weighted blanket to get the child to sleep	36 (72)	3 (6)	4 (8)	4 (8)	3 (6)
Provide child with favorite object (i.e., stuffed animal) [b]	18 (36)	2 (4)	6 (12)	7 (14)	16 (32)
Adjust lights to help with sleeping	18 (36)	1 (2)	4 (8)	8 (16)	17 (34)
Use preferred fabric of bedding	42 (84)	1 (2)	0 (0)	1 (2)	4 (8)
Wear preferred or no pajamas	30 (60)	1 (2)	7 (14)	7 (14)	4 (8)
Use noise machine or music	34 (68)	1 (2)	3 (6)	3 (6)	8 (16)
Follows specific routine for bedtime	9 (18)	1 (2)	3 (6)	17 (34)	18 (36)

Note. In some subsections N < 50 due to incomplete responses.
[a]Most frequently reported modification used during sleep-related activities sometimes to always.
[b]Second most frequently reported modification used during sleep-related activities sometimes to always.

Table 6

Percentage of Reported Use of Sometimes to Always in all ADL and Sleep-Related Areas of Occupation

ADL & Sleep-Related Activities	**Percentage (%)**
Dressing	26
Bathing and Grooming	31
Toileting and Bathroom	15
Eating, Mealtime, Snacktime	30
Sleeping	48

Table 7

Reported Frequency of Engagement in Activities Related to IADL Performance

	Frequency n (%)				
Tasks in the Home	Never	Rarely	Sometimes	Often	Always
Dressing					
Wash clothes	37 (74)	5 (10)	3 (6)	3 (6)	1 (2)
Dry clothes	38 (76)	3 (6)	4 (8)	3 (6)	1 (2)
Fold clothes	36 (72)	4 (8)	5 (10)	3 (6)	0 (0)
Put clothes away[b]	24 (48)	4 (8)	9 (18)	9 (18)	3 (6)
Bathing/Groom					
Getting supplies	29 (58)	2 (4)	7 (14)	10 (20)	2 (4)
Return supplies	28 (56)	3 (6)	6 (12)	12 (24)	1 (2)
Clean bathroom	39 (78)	2 (4)	4 (8)	3 (6)	0 (0)
Eating/Mealtime					
Help prepare	23 (46)	9 (18)	8 (16)	6 (12)	3 (6)
Set table	28 (56)	5 (10)	7 (14)	6 (12)	3 (6)
Clean up[a]	6 (12)	6 (12)	19 (38)	9 (18)	9 (18)
Sleeping					
Make bed	33 (66)	4 (8)	6 (12)	1 (2)	4 (8)
Change sheets	42 (84)	0 (0)	3 (6)	3 (6)	2 (4)
Set alarm clock	46 (92)	0 (0)	3 (6)	1 (2)	0 (0)
Pet Care					
Feed pet	20 (40)	3 (6)	4 (8)	7 (14)	1 (2)
Walk pet	23 (46)	1 (2)	5 (10)	4 (8)	0 (0)
Groom pet	30 (60)	1 (2)	1 (2)	2 (4)	0 (0)
Pet animal	11 (22)	3 (6)	4 (8)	7 (14)	9 (18)

Note. In some subsections N < 50 due to incomplete or no responses.
[a]Most frequently reported modification used during IADL-related activities sometimes to always.
[b]Second most frequently reported modification used during IADL-related activities sometimes to always.

Table 8

Reported Frequency of Use for Varying Means of Communication & Transition Methods

ADL & Sleep-Related Activities	Percentage of Respondents (%)							
	Means of Communication				Transition Method			
	Verbal	Tech Devices	PECS	Sign Language	Timer	Schedule Board	Object	Reward Chart
Dressing	82	5	4	4	23	15	11	8
Bathroom/ Grooming	77	7	4	5	2	9	7	4
Toileting/ Bathroom Use	76	7	2	4	9	4	7	7
Eating, Mealtime/ Snacktime	73	7	2	5	6	9	7	7
Sleeping	76	4	0	2	8	6	4	4

Note. Percentages may not equal 100% due to no response or multiple methods reported.

APPENDIX A

SURVEY

Modifications of the Home Environment and the Routines in Families of Children Diagnosed with an Autism Spectrum Disorder (ASD)

Jessica Ashe, OTS
Tiffany Cunningham, OTS

University of Puget Sound
School of Occupational Therapy and Physical Therapy
February 2013

Listed below are some suggested modifications used to help children with an ASD succeed in daily activities. Environmental modifications are changes made to the home. Routines are daily patterns that provide structure within the home.

Please read each line and circle "No" or "Yes" to indicate if the environmental modification is ***currently*** used in your home. If you circle "Yes," please indicate how often you, your family, or your child uses this modification. Additionally, please circle the most accurate means of communication and transition used during each activity.

If you have more than one child with a diagnosis of an ASD, answer the questions as they relate to the oldest child with an ASD.

Demographic Information

Q1. How many children in your home have a diagnosis of an ASD?
Boy(s) (Please list ages): _____ _____
Girls(s) (Please list ages): _____ _____

Q2. Please list the ages of all other children without a diagnosis of an ASD who live in your home.
_____ _____ _____ _____

Q3. How many years has your child received occupational therapy services? _____

Q4. Has the OT or any other professional been in the home to suggest modifications and/or routine changes? No Yes
If yes, they were used: Rarely Sometimes Often Always

Q5. Are there any medical conditions that interfere with the child's independence in self-care?
_____
_____

Q6. What demographic region do you currently live in?

_____Northeast
Includes: Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, Pennsylvania, & New Jersey
_____Midwest
Includes: Wisconsin, Michigan, Illinois, Indiana, Ohio, Missouri, North Dakota, South Dakota, Kansas, Minnesota, & Iowa
_____South
Includes: Delaware, Maryland, Washington DC, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Mississippi, Alabama, Oklahoma, Texas, Arkansas, & Louisiana
_____West
Includes: Idaho, Montana, Wyoming, Nevada, Utah, Colorado, Arizona, New México, Alaska, Washington, Oregon, California, Hawai'i

Q7. Dressing

Environmental Modification	Do you use any of these modifications?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Remove tags or buy clothes without tags	No	Yes	1	2	3	4
B. Allow child to wear only his/her preferred clothes and/or brands	No	Yes	1	2	3	4
C. Buy seamless socks and/or other garments for child	No	Yes	1	2	3	4
D. Avoid clothing with elastic	No	Yes	1	2	3	4
E. Use only elastic to avoid buttons or zippers	No	Yes	1	2	3	4
F. Lay out his/her clothing in a certain order	No	Yes	1	2	3	4
G. Follows specific routine to dress	No	Yes	1	2	3	4
H. Other (optional):			1	2	3	4
I. Other (optional):			1	2	3	4
**Means of Communication:*	Verbal	Tech Devices	PECS	Sign language		
***Transition Method (if any):*	Timer	Schedule Board	Object	Reward Chart		

* Tech Devices = use of iPad, Dynavox, etc. PECS = use of pictures

** Schedule Board = use of pictures/symbols Object = use of favored toy

Q8. Bathing & Grooming

Environmental Modification	Do you use any of these modifications?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Avoid showers (use tub baths instead)	No	Yes	1	2	3	4
B. Minimize length of time/frequency of hair washing	No	Yes	1	2	3	4
C. Only use a certain type of comb or brush	No	Yes	1	2	3	4
D. Allow child to not brush hair	No	Yes	1	2	3	4
E. Use a special strategy for tooth brushing	No	Yes	1	2	3	4
F. Use a particular toothpaste which child tolerates	No	Yes	1	2	3	4
G. Use special object (toy, earplugs, etc.)	No	Yes	1	2	3	4
H. Follows specific routine for bathing/grooming	No	Yes	1	2	3	4
I. Other (optional):			1	2	3	4
J. Other (optional):			1	2	3	4

**Means of Communication:*	Verbal	Tech Devices	PECS	Sign language
***Transition Method (if any):*	Timer	Schedule Board	Object	Reward Chart

* Tech Devices = use of iPad, Dynavox, etc. PECS = use of pictures

** Schedule Board = use of pictures/symbols Object = use of favored toy

Q9. Toileting & Bathroom Use

Environmental Modification	Do you use any of these modifications?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Use a schedule board with pictures/ symbols to show bathroom times	No	Yes	1	2	3	4
B. Warn child before flushing toilet	No	Yes	1	2	3	4
C. Allow child to use only his/her preferred bathroom	No	Yes	1	2	3	4
D. Use a special toilet seat for child	No	Yes	1	2	3	4
E. Use particular toilet paper or wipes, preferred by child	No	Yes	1	2	3	4
F. Allow child not to flush toilet, if frightened by it	No	Yes	1	2	3	4
G. Keep toilet paper out of child's reach	No	Yes	1	2	3	4
H. Use a latch on toilet	No	Yes	1	2	3	4
I. Follows specific routine for toileting	No	Yes	1	2	3	4
J. Other (optional):			1	2	3	4
K. Other (optional):			1	2	3	4

**Means of Communication:*	Verbal	Tech Devices	PECS	Sign language
***Transition Method (if any):*	Timer	Schedule Board	Object	Reward Chart

* Tech Devices = use of iPad, Dynavox, etc. PECS = use of pictures

** Schedule Board = use of pictures/symbols Object = use of favored toy

Q10. Eating, Mealtime, & Snacktime

Environmental Modification	Do you use any of these modifications?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Provide an alternative seating	No	Yes	1	2	3	4
B. Allow child to stand at table during meals	No	Yes	1	2	3	4
C. Serve food in preferred manner (i.e. not touching, one item per plate)	No	Yes	1	2	3	4
D. Allow child to eat with hands or use preferred utensils	No	Yes	1	2	3	4
E. Serve only what your child will eat, no new foods	No	Yes	1	2	3	4
F. Serve only a certain shape or color of food for your child	No	Yes	1	2	3	4
G. Serve only a certain texture of food for your child	No	Yes	1	2	3	4
H. Follows specific routine for eating	No	Yes	1	2	3	4
I. Other (optional):			1	2	3	4
J. Other (optional):			1	2	3	4

**Means of Communication:*	Verbal	Tech Devices	PECS	Sign language
***Transition Method (if any):*	Timer	Schedule Board	Object	Reward Chart

* Tech Devices = use of iPad, Dynavox, etc. PECS = use of pictures

** Schedule Board = use of pictures/symbols Object = use of favored toy

Q11. Sleeping

Environmental Modification	Do you use any of these modifications?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Engage in routine or rituals when putting your child to bed	No	Yes	1	2	3	4
B. Provide weighted blanket to get the child to sleep	No	Yes	1	2	3	4
C. Provide child with favorite object, such as stuffed animal	No	Yes	1	2	3	4
D. Adjust lights to help with sleeping	No	Yes	1	2	3	4
E. Use preferred fabric of bedding	No	Yes	1	2	3	4
F. Wear preferred or no pajamas	No	Yes	1	2	3	4
G. Use noise machine or music	No	Yes	1	2	3	4
H. Follows specific routine for bedtime	No	Yes	1	2	3	4
I. Other (optional):			1	2	3	4
J. Other (optional):			1	2	3	4

**Means of Communication:*	Verbal	Tech Devices	PECS	Sign language
***Transition Method (if any):*	Timer	Schedule Board	Object	Reward Chart

* Tech Devices = use of iPad, Dynavox, etc. PECS = use of pictures

** Schedule Board = use of pictures/symbols Object = use of favored toy

Q12. Helping at Home

Tasks in the Home	Does your child help with these tasks?		How often? (Circle the one most accurate for you) Rarely	Sometimes	Often	Always
A. Dressing:						
Wash clothes	No	Yes	1	2	3	4
Dry clothes	No	Yes	1	2	3	4
Fold clothes	No	Yes	1	2	3	4
Put clothes away	No	Yes	1	2	3	4
B. Bathing/Groom:						
Getting supplies	No	Yes	1	2	3	4
Return supplies	No	Yes	1	2	3	4
Clean bathroom	No	Yes	1	2	3	4
C. Eating/Mealtime:						
Help prepare	No	Yes	1	2	3	4
Set table	No	Yes	1	2	3	4
Clean up	No	Yes	1	2	3	4
D. Sleeping:						
Make bed	No	Yes	1	2	3	4
Change sheets	No	Yes	1	2	3	4
Set alarm clock	No	Yes	1	2	3	4
D. Pet Care:						
Feed pet	No	Yes	1	2	3	4
Walk pet	No	Yes	1	2	3	4
Groom pet	No	Yes	1	2	3	4
Pet animal	No	Yes	1	2	3	4

Please use the space below for any comments or clarifications.

_____

_____

_____

_____

Thank you for participating in this research.

Your contributions are very much appreciated!

(Please return the survey at your earliest convenience)

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Tacoma, WA. 98416-1070

APPENDIX B

February 21, 2013

Hello,
Thank you for your willingness to participate in our study: Modifications of the Home Environment and the Routine in Families of Children Diagnosed with an Autism Spectrum Disorder (ASD).
This package contains several items to help educate the staff and parents of children with a diagnosis of an ASD about our study:

1. Script for Administrative Assistants and/or the Occupational Therapists to give to the parents of a child with an ASD.

2. Flyer that gives succinct information about the study
    a. To be hung for families to view

3. Purpose and Procedures document outlining the study
    a. Posted near the flyer for families to view

4. IRB Approval document for this study
    a. For the facility's record

5. Survey Packet containing cover letter, survey booklet, and postage-paid envelope
    a. *Postage-paid envelop* is for the parents to send the survey directly back to the researchers
    b. Administrative assistants or therapists *do not need to send the survey* since the parents have the pre-paid envelop – this is important to know

In two weeks, we will call or email your facility to check on the distribution of the surveys. We need the surveys sent back to us by **March 20th**. This date allows us to analyze our data, write up our findings, and graduate from our occupational therapy program at the University of Puget Sound.
Again, thank you for your willingness to participate in our study. If you have any questions, please contact our faculty advisor listed below.

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Tiffany Cunningham, OTS

UNIVERSITY OF PUGET SOUND
School of Occupational Therapy & Physical Therapy

Hello,

This is a script for the administrative assistants or occupational therapists when asking primary caregivers to participate in our study. This guide for the staff is intended to help with distribution of the survey packets.

Administrative Assistant (AA) and/or Occupational Therapist (OT):

"Good afternoon. Would you be willing to participate in a survey being conducted by occupational therapy graduate students at the University of Puget Sound in Tacoma, Washington? The survey is looking at different modifications made to the home environment and the routines of families raising a child diagnosed with an Autism Spectrum Disorder (ASD) when performing daily living skills.

The survey should only take about 15 minutes. You can take it home or fill it out here – but please send it back to the research survey team via the pre-paid envelope included in this packet as soon as possible. They need it by **March 15th.** We hope that your information can inform clinicians and other parents about strategies that families use to assist their child in being successful in self-care skills and life skills.

Thank you so much for considering assisting the graduate students in this research project."

<u>If caregiver responds no, then:</u>

AA and/or OT: Okay. Thank you for your time.

Home Modifications & Autism Spectrum Disorders (ASD)

How do you help your child participate in daily life?

Ask how you can help with OT student research!

University of Puget Sound
School of Occupational and Physical Therapy

UNIVERSITY OF PUGET SOUND
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Project Title: Modifications of the Home Environment and the Routine in Families of Children Diagnosed with an Autism Spectrum Disorder

Researchers: Jessica Ashe, OTS and Tiffany Cunningham, OTS
Research Advisor: Marge Luthman, MS, OT/L

Purpose: The purpose of this study is to identify caregiver-mediated modifications of routines and home environments in families of children with an ASD throughout the U.S. that are believed to facilitate the child's enhanced participation in daily life.

Procedures: After review and approval from the university Institutional Review Board (IRB), the modified survey will be piloted on four primary caregivers of a child with an ASD. Feedback will be used to make adjustments before distributing the survey. Contact information of participating clinics will be gathered by researchers. Telephone contact will then be made to reinforce their assistance with the study and inquire about clinic procedures or institutional protocol before beginning research. Upon agreement, clinics will be sent a package containing survey packets, a script for distribution, a flyer, and a copy of the study's IRB approval. Participants meeting the inclusion criteria will be asked by the administrative assistant or their current occupational therapist if they want to participate in the present survey. If they agree to participate, they will be given a packet containing materials needed to complete and return the survey to the researchers. A follow-up phone call will be made to the administrative assistant two to three weeks after the survey packets are mailed. Researchers will inquire about distribution of the surveys and address any questions or concerns during this time.

If clients do or do not want to participate, they can be assured of complete confidentiality. This includes the child's therapist and other employees at the clinic, who will not know if a family choose to complete the survey or not. Neither the name, nor any other identifying information will be included in the survey, research findings, or presentation materials.